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"It's a huge maze, the system, it's a terrible maze": Dementia carers' constructions of navigating health and social care services

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Abstract

Dementia is a challenging, progressive set of conditions which present a large care burden to informal, familial carers. A complex array of health and social care services are needed to support people living with dementia. Drawing on the interlinked 'Duties to Care' and 'Dementia Talking' projects, in this article we focus on British carers' talk about health and social care services. We explore data from a mixed-method questionnaire (n=185), four focus groups and eleven interviews with informal carers of people living with dementia using thematic discourse analysis. Three themes are discussed: 1) services as a 'maze'; 2) services as overly limited – 'beyond our remit'; and 3) the battle and fighting discourse deployed by these carers. Our analysis highlights that carers find navigating systemic issues in dementia care time-consuming, unpredictable and often more difficult than the caring work they undertake.

Keywords

Alzheimer's Disease, Carer, Dementia, Discourse Analysis, Health and Social Care Services

Introduction

Dementia is an extremely common condition, which predominantly affects older people. Alzheimer's Disease International (2009) estimates that there were 35.6 million people living with dementia worldwide in 2010; a number which is projected to increase to 65.7 million by 2030. Research commissioned by the Alzheimer's Society, estimates that there were 683,597 people living with dementia in Britain in 2007 (Knapp et al., 2007). This figure includes at least 15,034 people with younger onset dementia (dementia diagnosed before the age of 65), and the total numbers of people affected in the UK alone are estimated to increase to over 1 million by 2021, given trends towards an ageing population. Health and social care provision for people with dementia demands the complex organisation of multiple different services that range from those focused on social and community engagement (such as day centres, or activities facilitated by a support worker) to those involving aspects of personal care (such as continence services, Drennan et al., 2011) and health care (such as physiotherapy for dysphagia, residence in a care home). Moreover, because the dementia journey is typically a lengthy, and often step-wise process, need for different services both incrementally increases over time, but can also be required quite suddenly when there is, for example, an acute change in an individual's functioning due to a worsening of symptoms, or delirium (a treatable medical emergency) associated with other health problems such as infections.

Notwithstanding the prevalence of dementia and the complexity of dementia care provision, historically dementia service provision and the role of carers has been a neglected issue (Innes, 2002). Existing research has identified an underutilisation of services and focused on unmet service needs (e.g., Brodaty et al., 2005; Innes et al., 2005; Lloyd & Stirling, 2011; Stirling et al., 2010). Over half of the 45 participants (58%) in Innes et al.'s (2005) interview study in Scotland, for instance, had refused services that had been offered to them because they were unsuitable for their needs. Reasons given for refusal were complex and multi-layered, but included: distress to the service users, feelings of guilt, a desire to remain at home, feeling able to cope and wanting to protect privacy. These justifications reflect the findings of Brodaty et al.'s (2005) research in Tasmania, which identified reluctance to use services as one of four categories of service non-use, alongside carers' perceived lack of need for services, unsuitable service characteristics, and lack of knowledge

of available services. Findings from a systematic review of information provision services in a dementia care context (Corbett et al., 2012) suggest that the provision of information and services do not provide significant benefits to carers, as measured through carer burden scales, though they can have positive effects on people living with dementia.

As such, there is a paradox evident in the literature in this area between the ubiquity and understandings of carer strain or burden on the one hand, and the reported lack of uptake of, resistance to, and limited benefit of dementia services for carers on the other. Lloyd and Stirling (2011) have recently developed the concept of 'ambiguous gain' or unclear benefit to unpack the potentially negative impact that contact with dementia services can have on carer identities. They argue that "when experienced by dementia carers, ambiguous gain can be understood as a product of a mismatch between the operational logics of bureaucratic 'systems' and domestic 'lifeworlds'" (Lloyd & Stirling, 2011: 900). Whereas carers seek support services that correspond with their everyday relational experience, and that follow common sense reasoning, institutional providers develop services that address institutional rationalities of objectivity and efficiency. These two oppositional approaches seem to conflict, which could account for some of the empirical findings of lack of engagement with and use of services designed to assist carers of people living with dementia.

While this previous work is valuable, we are critical of the (implicit) positioning of carers within a deficit model - as 'lacking' or in some sense 'failing' to fully or appropriately engage with the services that are offered to them. Our approach, in contrast, was to explore the issue of accessing health and social care support services from carers' own perspectives. In so doing, we did not presuppose that carers would necessarily be resistant to dementia services, but rather that participants would hold a complex range of views about the quality, scope and remit of services.

Method

Following University ethical approval data were generated through a tripartite data collection process exploring carers' of people with dementia's experiences of access to, and the regulation of, health and social care support services for people with dementia. These data are drawn from two connected research projects ('Duties to Care' and 'Dementia Talking'), which included a multi-method online and paper questionnaire (n=185), followed up with four focus groups (n=15) and eleven semi-structured in-depth interviews (see also Harding and Peel, 2012; Peel in press). A total of 190 individual carers of people with dementia participated in this research.

These methods were chosen to explore the perspectives of carers in a number of different ways; the questionnaire was designed to gain both an overview of carers' experiences and as mechanism for recruiting participants to the more in-depth focus groups and interviews. The questionnaire was divided into four sections. Section 1 asked for detailed demographic and contextual information including how much care the respondent was providing, where the person living with dementia was residing, and information about diagnosis and medication. Section 2 focused on service provision, asking about contact with health and social care professionals and services and views about care provision. Section 3 asked about respondents views about legal and financial rights and responsibilities, including 'power of attorney' and complaints. The final section was about support and information and included the Caregiver Strain Index (Robinson, 1983). Semi-structured, in-depth interviews and focus groups were utilised to explore carers' experiences in more detail. This mixed-method approach allowed us to take a pragmatic approach, and gain both an overview of the issues that carers raised, and capitalise on the strengths of quantitative and qualitative methods (Morgan, 2007). We utilise triangulation as a methodological metaphor in order to draw together the quantitative and qualitative aspects of our findings (Östlund et al., 2011) to give a deeper and clearer picture of carers' experiences and constructions of services than single method studies can achieve.

Data Collection and Participant Demographics

Table 1: Questionnaire Demographics

	Carers			People with dementia		
Age Range	Min	Max	Mean	Min	Max	Mean
Years	26	87	62.6	44	97	76.2
	N	%		N	%	
Gender						
Female	128	69.2		97	52.5	
Male	56	30.3		87	47	
Total	184	99.5		184	99.5	
Race						
White British	161	87		157	84.9	
White Irish	6	3.2		7	3.8	
White Other	13	7		16	8.6	
Mixed (White and Asian)	1	0.5		2	1.1	
Black African	1	0.5		0	0	
Asian Other	1	0.5		0	0	
Mixed (Other)	0	0		1	0.5	
Total	183	98.9		183	98.9	
Disability						
Reported disability	42	22.7		140	75.7	
No disability	143	77.3		45	24.3	
Total	185	100		185	100	
Sexual Orientation						
Heterosexual	180	97.3		180	97.3	
Bisexual	2	1.1		0	0	
Total	182	98.4		180	97.3	
Religion						
No religion	37	20		30	16.2	
Christian	139	75.1		149	80.5	
Buddhist	2	1.1		0	0	
Jewish	2	1.1		0	0	
Muslim	1	0.5		3	1.6	
Other	3	1.6		2	1.1	
Total	185	100		185	100	
Self-defined Social Class						
Middle Class	109	58.9		100	54.1	
Working Class	73	39.5		77	41.6	
Other	1	0.5				
Total	183	98.9		177	95.7	

Questionnaire respondents were recruited through strategic opportunistic and snowball sampling via relevant charitable/third sector organizations including carers groups and support services. Paper recruitment packs were posted to a total of 461 dementia and/or care-focused support groups run by the Alzheimer's Society and the Princess Royal Trust for Carers (now Carers Trust). These paper packs were followed up a fortnight later with email reminders. Recruitment emails were sent to an additional 13 dementia-related organisations, and recruitment details were posted on four online discussion forums. The questionnaire was live for a period of four months, between February and May 2011. Carers could either complete the questionnaire online (n=154) or contact the research team for a postal questionnaire pack (n=31).

Table 2: Focus Group Demographics

Pseudonym	Age	Class	Person care for/ age	Type of dementia	Residence of PWD	Caring Status
Chloe (FG1)	58	Middle class	Mother, 84	Vascular dementia	Nursing home	Ex-carer
Laura (FG1)	55	Working class	Father, 88	Vascular dementia	Nursing home	Current
Peter (FG1)	58	Working class	Mother, 92	Mixed: Alzheimer's and Vascular	Own home	Current
Viv (FG2)	64	Middle class	Husband, 68	Parkinson's disease with Lewy Body Dementia	Own home	Current
Morris (FG2)	78	Middle class	Wife, 71	Front-temporal dementia	Own home	Current
James (FG2)	47	Middle class	Mother, 77	Vascular dementia	Own home	Ex-carer
Sarah (FG2)	67	Middle class	Husband, 70	Fronto-temporal dementia	Own home	Current
Gwen (FG2)	-	Middle class	Husband, -	Lewy Body Dementia	Nursing home	Ex-carer
Graham (FG3)	87	Working class	Wife, 86	Alzheimer's	Own home	Current
Angela (FG3)	67	Middle class	Husband, 74	Alzheimer's	Nursing home	Current
Sandra (FG3)	62	Working class	Husband, 80	Vascular dementia	Nursing home	Current
Jean (FG3)	72	Middle class	Husband, 75	Alzheimer's	Nursing home	Current
Margaret (FG4)	77	Middle class	Husband, 81	Vascular dementia	Nursing home	Current
Tom (FG4)	73	Middle class	Wife, 69	Alzheimer's	Own home	Current
Alan (FG4)	59	Working class	Mother, 89	Alzheimer's	Own home	Current

Given the varied nature of the recruitment strategy, it is difficult to assess the response rate, though a basic calculation of number of completed questionnaires (185)/number of recruitment messages, emails and postal contacts (939), suggests a response rate of just under 20% overall. However, the actual response rate for carers finding out about the study could be much higher as, except for the four online forums, we did not contact carers directly but rather relied on the goodwill of

'gatekeepers' such as support group co-ordinators. Participants in the focus groups and interviews were predominantly recruited from within the questionnaire responses. There was no overlap in the carers who participated in the focus groups and the interviews. Table 1 provides outline demographic information for questionnaire respondents, and the people they care for. The majority of respondents were women (n=128, 69.2%) caring for roughly equal numbers of men (87, 47%) and women (97, 52.5%). Respondents were overwhelmingly white (97.2%) and heterosexual (97.3%), with a mean age of 62.2 years. A majority identified their religion as Christian (n = 139, 75.1%). Most carers (n = 143, 77.3%) reported no disability, though just under a quarter (n = 42, 22.7%) reported having a disability, including: arthritis, cancer, diabetes and mobility impairment.

Fifteen participants attended four focus groups held in two large cities and two towns in central and southern England between September and December 2011. A total of 34 people were invited to participate in focus groups, and originally 18 carers had agreed to participate, but three were not able to attend on the day. The response rate for focus group participation was therefore 44%. All participants were white and heterosexual. In total 8 hours 40 minutes of focus data were collected, with each group lasting around two hours.

Table 3: Interview Demographics

Pseudonym	Age	Class	Person care for/ age	Dementia type	Residence of PWD	Caring status
Victoria	63	Middle class	Mother, 88	Alzheimer's	Own home	Current
Carlos and Anne	58	Working class	Father, 87	Alzheimer's	Own home	Ex-carer
Jan	58	Working class	Mother, 87	Vascular dementia	Residential home	Current
Emma	79	Middle class	Husband, 83	Vascular dementia	Residential home (self-funding)	Current
Sue	59	Working class	Mother, 87	Vascular dementia	Residential home (self-funding)	Current
Derek	65	Working class	Mother, 86	Vascular dementia	Own home	Ex-carer
Maureen	60	Middle class	Mother, 95	Alzheimer's	Nursing home (self-funding)	Ex-carer
Kaylet	59	Working class	Husband, 67	Fronto-temporal dementia	Own home	Current
Jonathan	67	Middle class	Wife, 66	Fronto-temporal dementia	Nursing home (NHS continuing care)	Current
Mick	70	Working class	Wife, 68	Alzheimer's	Nursing home (NHS continuing care)	Current
Pamela	56	Middle class	Husband, 60	Fronto-temporal dementia	Own home	Current

As we can see from Table 2, nine (60%) of the participants were women, six (40%) were men and their mean age was 66 years (range 47-87). The majority (12, 80%) were currently caring and three participants were bereaved. Ten (67%) participants defined as middle class, while five (33%) defined

as working class. Ten (67%) were caring for a spouse, while five (33%) were caring for a parent. The mean age of the person the participants cared for was 78.9 years (range 69-92) and they had been diagnosed with a range of dementias: five (33%) with Alzheimer's disease; five (33%) with vascular dementia; two (13%) with Lewy Body dementia; two (13%) with fronto-temporal dementia and one with mixed Alzheimer's and vascular dementia. About half of the people with dementia resided in their own home and half in a care home.

Table 3 provides demographic information about carers who were interviewed. Interviews ranged from 1 hour 16 minutes to 2 hours 7 minutes (mean length 1 hour 37 minutes) and were conducted in participants' homes between November 2011 and January 2012. Most interviews were conducted in the Midlands, three were conducted in the North of England and two in the South. All participants were white and all identified as heterosexual apart from one bisexual woman. Eighteen potential interviewees were invited to participate therefore the response rate was 61%, although only two carers who were contacted actively declined participation. Interviewees mean age was 63 years (range 56-79) and the mean age of the person they cared for was 79.5 years (range 60-95).

Data Analysis

Two closed questions and a number of likert-type rating scale statements (1 = strongly agree; 5 = strongly disagree) were used to generate quantitative data about service provision, support and information in the questionnaire. Quantitative results were analysed using IBM® SPSS® Statistics 20 for frequencies and bivariate relationships. T-tests and chi-square analysis were used to explore differences between groups on the basis of demographic variables, levels of carer strain, relationship to the person with dementia, and where the person with dementia lived (own home/formal care and with/without informal carer). In addition, we elicited qualitative data about health and social care and support through broad open questions. These questions were asked in all three data collection methods (questionnaire, focus group, interview) - What, if any, support do you receive from others? What do you feel are the most important issues facing carers of people with dementia?; or in the focus groups and interviews - Can you tell us/me a bit about your experience of caring for someone with dementia? Can you tell us/me about a high point in your experience of caring for a person with dementia? Can you tell us/me about a low point in your experience of caring for a person with dementia? Qualitative results from the focus groups and interviews were independently coded by the research team, using both deductive and inductive codes. Deductive codes were generated from the project research questions, inductive codes emerged as patterns within the data through repeated reading and re-reading of the transcripts. Akin to much of our previous research (e.g., Peel et al., 2005, 2006) in the analysis that follows we take a broadly discursive psychological approach to these data (Edwards & Potter, 1992), being mindful of the types of actions (i.e., justifying, complaining) participants are accomplishing as well as the topical focus of their talk. Therefore, our thematic discourse analysis focuses on both the rhetorical design of the themes and on their ideological implications.

Findings

Most participants (78.5%, 142) were 'under strain' as indicated by their responses to the Caregiver Strain Index, which was embedded in the questionnaire. No significant associations were found in chi-square analyses on demographic variables, dementia diagnosis, severity of dementia, medications prescribed or where the person with dementia lives which would account for these high levels of carer strain. In spite of this, just half (51%, 92) reported having ever been offered a carers assessment of their own needs, which is a legal entitlement, implemented by the Carers (Equal Opportunities) Act 2004, and operationalised through social services for people who provide 'regular' and 'substantial' care. Participants reported engaging in high levels of support and information seeking: most had accessed websites (82%, 152); joined a membership organisation (e.g., Alzheimer's Society) (69%, 128); read books (68%, 125); accessed health professionals (61%, 113); or a support group (55%, 102). A large minority (40%, 74) had utilised online support groups

and only 3% (5) had not accessed any sources of support or information. As shown in Table 4, while the majority reported having a General Practitioner (GP, or family doctor) involved with the person they care for, only half (48%, 89) indicated input from a psychiatrist and only a quarter (23%, 43) from a neurologist.

Table 4: Involvement of health or social care professionals

GP (family doctor)	86% (156)
Psychiatrist	49% (89)
Social Worker	41% (75)
Community Psychiatric Nurse (CPN)	33% (59)
Neurologist	24% (43)
Care home staff	28% (50)
Nurses (care home)	22% (40)
Home help	12% (22)

About half of participants (54%, 97) agreed that 'overall, the standard of care the person I care for receives from professionals is excellent'. Male respondents (M = 2.26, SD = 0.894) were more likely to agree (t = -3.616, df = 113.262, two-tailed p = 0.000) with this statement than female respondents (M = 2.81, SD = 1.014).1 Respondents who care for a person with dementia who lives in formal care (M = 2.36, SD = 0.873) were also more likely to agree (t = 2.001, df = 171, two-tailed p = 0.047) that the standard of care the person with dementia receives from professionals is excellent. Carers who care for a person with dementia who lives at home (M= 2.72, SD 1.036) were more likely to be neutral about this statement. Less than a quarter of all respondents agreed that care staff in a residential (25%, 33) or community setting (23%, 31) are 'trained to an appropriate level'. Respondents caring for a person with dementia who lives in formal care (M = 2.84, SD = 1.128) were more likely to agree (t = 2.724, SD = 126, two-tailed p = 0.007) that care staff working in residential settings are trained to an appropriate level than respondents caring for a person with dementia who lives at home (M = 3.41, SD 1.059), who were more likely to disagree. These findings combine to suggest that more exposure to professional services increases carers' subjective ratings of their quality.

Importantly, carers reporting high levels of strain (M = 2.72, SD = 1.029) were less likely to agree (t = 2.019, df = 178, two-tailed p = 0.045) that the person they care for receives an excellent standard of care from professionals than carers reporting lower levels of strain (M= 2.36, SD = 0.873). Carers reporting high levels of strain (M = 2.6, SD = 1.130) were also more likely to agree (t = -2.123, df = 135, two-tailed p = 0.036) that care staff working in community settings are not appropriately trained. Furthermore, about a third (34%, 45) disagreed that 'care homes are appropriately regulated'. This reflects findings from previous research that carers under strain may have complex reasons for not accessing formal sources of support.

The majority of respondents agreed (59%, 103) that 'professionals involved with the person I care for are knowledgeable about dementia'. However, about a third (32%, 58) agreed that professionals 'are not sensitive to my needs'. Female respondents (M = 2.95, SD = 1.179) were more likely to agree that professionals are not sensitive to their needs (t = 2.601, df = 177, two-tailed p = 0.010) than male respondents (M = 3.43, SD = 1.042). Similarly, respondents caring for a parent (M = 2.88, SD 1.191) were more likely agree (t = -1.989, df = 178, two-tailed p = 0.048) that 'professionals involved with the person I care for are not sensitive to my needs' than those caring for a spouse or partner (M = 3.23, SD = 1.115). These findings suggest that services have developed or are provided in ways that are not necessarily congruent with the needs and expectations of informal caregivers. Our qualitative findings provide deeper interrogation of these quantitative findings. In the remainder of

[1] Because the variances for the two groups were unequal (F= 4.548, $p = 0.034$) a *t*-test for unequal variances was used.

our analysis we focus on three interlinking themes in participants' talk about accessing services: 1) services as a 'maze'; 2) services as overly limited – 'beyond our remit'; and 3) the battle and fighting discourse deployed by these carers.

Service Provision as a Maze

Most participants expressed negative views about 'the system' as a whole - 'it wasn't a benevolent system' (Sue, I42) - and voiced systemic problems with both accessing, and navigating, health and social care services for the person they cared for. The prevalence of the metaphor of a maze – an intricate and typically bewildering network of pathways – was deployed in participants talk to signal the confusion, complexity, wrong-turns and dead ends that they had encountered in their interactions with the dementia services system. Interestingly, this metaphor is utilized, and subverted, in other contexts. For example, Monthly Alzheimer's Support Evening (MASE) - with an image of a maze on their publicity leaflet - is a local support group for 'carers and cared for through their journey with dementia' which operates in rural Staffordshire, UK. Presumably, although this is implicit, the name of the group evolved in recognition of the complexity and uncertainty surrounding dementia and the need for sharing experiences and peer support to successfully navigate the maze. For example, Viv (FG2), who was caring for her husband at home, emphasised and re-emphasised the complexity and frustration with systemic issues in the provision of dementia care: 'It's a huge maze, the system, it's a terrible maze and you- you come up against, I won't say brick walls, but, you know, dead ends practically everywhere you turn'. We can see here that she upgrades her original assessment of the maze from simply expansive ('huge') to something that is unpleasant ('terrible') for rhetorical effect to strengthen her point (Schegloff et al., 1977). She uses the plural 'we' rather than the singular to indicate that this is a shared, generic experience rather than something idiosyncratic, and the discourse marker 'you know' also strengthens this sense of a shared general truth between those present (Schiffrin, 1987). Using the phrase 'I won't' signals, by implicit contrast, that she could, in fact, describe the difficulties with navigating dementia care services in such absolutely and impenetrable terms as 'brick walls' but in downgrading this portrayal to 'dead ends' and avoiding an extreme case formulation ('practically' rather than 'always' for instance, Pomerantz, 1986) she presents the analogy in a particularly compelling way.

Anne (I2) through her comment 'first of all you've got to find out what the system is and then you've got to deal with it' highlights the foundational nature of the problem without recourse to the maze metaphor. In her talk here 'the system' is simply an unknown – which although in some senses is less problematic than the maze analogy, it also alludes to the closed nature of 'the system' and to the steep learning curve carers can face. The phrase 'then you've got to deal with it' carries a heavy embedded freight. Carlos, Anne's husband, who was the primary carer for his father who had lived in his own home until his death, a few months prior to interviewing them both, provides a more explicit account (see Extracts 1). Jonathan, whose wife lived in a specialist nursing home funded through NHS continuing healthcare,3 was similarly explicit. As we will see, the two accounts below are interesting for a number of reasons - the carers diverge in terms of class background, funding status, and location of care – and yet the shared central 'frustration' and 'main challenge' was firmly constructed as 'the system'.

[2] Participants are labelled with their pseudonym and also the method of data collection: interview (I), focus group (FG) or questionnaire (Q).

[3] NHS continuing healthcare is care funded solely through the NHS and is free at the point of use for all, unlike social and community care services provided by local authorities and social services which are means tested. Because care needs in dementia straddle the health and social/personal care divide it can be very difficult for people with dementia, or those familial carers advocating on their behalf, to gain access to fully funded NHS care.

Extracts 1

Er, the system was, the frustration, me Dad was enough work, right, but Social Services and the system was even worse. To get anything done it- it- it was- it was always, you always, you had to wait for something to happen, for him to get into that condition before anybody did anything about it, and then by the time they'd done it you don't need it because you're moving onto the next stage. (Carlos, I2)

I think the main- the main challenge I've had is trying to keep up with the system and- and work out what's going on. Because, like most aspects of life, you suddenly are di- you dive into NHS mental health policy, which you don't know about before. Um at least I've got some idea of organisation because I've worked for the city council for most of life um, and so I know how organisations work or don't work. Um so I wasn't fazed by issues to do with PCTs and Health Trusts and this sort of thing. But it is quite complicated [...] But I think it- it's quite wearing in a way. How- how do I navigate my way through the system without putting my foot on something? Um, I don't [laughs] (Jonathan, I9)

We can see here that both Carlos and Jonathan construct accounts in ways that emphasise that the issues they encountered in accessing and navigating the dementia care system – be it social care or health care – in fact eclipse other aspects of their experience of caring for a person with dementia. One could envisage a very different set of narratives whereby the degenerative, complex and challenging nature of the different manifestations of the disease itself take centre stage. Indeed, both these carers at other points during interview described very challenging and distressing situations: 'within the space of a week your Dad lost nearly all his mobility didn't he, nearly all his speech and became doubly incontinent day and night' (Anne, I2). Jonathan's wife had been 'Sectioned'4 twice because of her extremely challenging 'gross' behaviours. Yet it was systemic failings which were the 'punch line' of these accounts rather than the difficulties per se. Anne concluded, 'and that's where a fourteen to sixteen week waiting list at an incontinence clinic is absolutely no good' (Anne, I2); and Jonathan said 'it was the worst time of my life' because there 'was with a discharge plan saying that if things went wrong she wasn't to be readmitted and er I- it was pretty, pretty desperate really'.

In Extracts 1 the contrast between caring being 'enough work' – that is sufficiently difficult in and of itself – and Social Services being 'even worse' underscores the extremity of the situation. The lack of timeliness in, in Carlos' case, home service provision (in terms of hoist, specialist bed, continence services, district nursing, home visits from care staff and so on) was especially poignantly reflected in the provision of an isolating mattress and a hoist: 'they were going to deliver it on the Monday, he died on the Friday'. We return to this and focus on the compartmentalisation of services in the next theme. Jonathan, by contrast, juxtaposes prior knowledge and experience of 'how organisations work' and not 'being fazed' by organisational and institutional complexity per se with the dementia health care system being 'the main challenge' and the (understated) phrase 'quite complicated'. Carlos' father was entitled to social services support but Jonathan and his wife would be self-funding her care if NHS continuing healthcare were not available to them, as a result of her complex care needs stemming from her non-cognitive symptoms.

That Jonathan constructs the situation in Extracts 1 as 'quite wearing' glosses the position he states explicitly elsewhere: 'I'm constantly looking over my shoulder in terms of funding and so on'. The way in which he describes their "privileged" situation regarding payment for care is also interesting for a number of reasons: 'we've been incredibly lucky so far, cos it's nine years entirely at NHS expense, which is too good to be true, and we're very lucky'. 'Luck', rather than a sense of

[4] Sectioned refers to being detained in hospital without consent under the Mental Health Acts.

entitlement – which is culturally a more prevalent discourse with respect to health care provision in the UK – or 'right' to care free at the point of delivery predominates in his account. For other participants too, the issue of how to navigate through the system in a way to maximise funding for care was their 'main worry' (Kaylet, I8). Here, in Extracts 1 Jonathan answers his rhetorical question about navigating through the maze-like system with the perfunctory 'I don't'. In the space between his production of himself as a competent, thinking, well-equipped individual able to deal with other systems and processes and the 'I don't' lies the vagaries and unknowns of a system which, although currently working in his family's "favour", isn't in fact properly navigable or trustworthy, as he says elsewhere: 'I don't trust the system and I have to try and understand the system'.

Beyond Our Remit

A second prevalent theme in these data was participants' talk about the compartmentalisation or fragmentary nature of services, a sense of exclusion from access to appropriate services and lack of access to rehabilitative service provision for the people with dementia they cared for. As Viv (FG2) encapsulated: 'I have heard this phrase more often from people in the caring and system than anything, "it isn't- it is beyond our remit, beyond our remit". I think I've heard that more than anything else'. In Extract 2, below, we can see how Jan (I3), who had been full-time carer for her mother prior to her moving into a residential home, constructs the partial nature of services as a 'nightmare'.

Extract 2

EP: Were there other things where you were kind of communicating with other agencies, whether it be Social Services or-

JA: Oh yeah.

EP: or, you know, other bodies that- that?

JA: I can feel the sinking in my stomach even now at the thought. You're- you're at your lowest ebb, you've been trying to keep all the plates spinning for a long time and you just need it to be easy. You just need to be able to make a phone call and somebody will say "yeah, we know that problem, we're with yer". But no, you've got to jump through hoops, it's not their department or, oh they can give you this number; you ring that number, they give you another number and you're just- that is a nightmare. The system is a nightmare. (Jan, I3)

Jan initially responds by describing a visceral reaction to the historical thought of the issue of interacting with service providers. This kind of emotion discourse could have a range of rhetorical functions (Edwards, 1999) but here it functions to foreground a sense of doom and inevitable negativity to what she then goes onto say, which she does using the plural 'we' to underscore that this is a shared and widespread experience rather than something which is particular to her. The phrase 'lowest ebb' suggests being dispirited in a protracted sense and the use of an extreme case formulation ('lowest', Pomerantz, 1986) here as well functions to enhance the contrast between the desperate nature that has precipitated the contact with services and the lack of support and empathy ('we're with yer') received. Viv, who was caring for her husband at home using a package of care funded through NHS continuing healthcare which was less comprehensive that he needed, highlights the sense of exclusion from direct access to information from services in Extract 3.

Extract 3

I said "which homes do you, do you have on your list?" which is a reasonable question, because they would fund it. "Which are the homes?" "Oh, I don't know, you've got to ask [name] that". Anyway, eventually I got on to [name] and I said "can you give me a list of the…?" "No, no", I rang- I rang the [name] Centre and I said "can you put me through to the NHS Continuing Care team?" And the person who answered the telephone said "no". I said "pardon?" I said "did you hear me, I said can you just please put me through to the Continuing Care team?" "No, they don't take calls". I said "what?" I said "well, why on earth not?" "Well, they only speak to each other" they only speak to people within the system. If I had been a social worker or somebody from the memory service or the GP or the- they would have spoken to each other. They all talk amongst themselves, but they won't talk to the client, it's just beyond their remit. So, um, I said "well, look, I'm trying to find out the names of the care homes that the NHS in [place name] either recommend or would pay money towards", blah… and she said "well, I can pass on the message, who shall I say is calling?" So I said "okay". So nothing happened, obviously nobody rang me back, nothing happened. I said- I rang back maybe two weeks later. I said "I rang two weeks ago and I asked for a list of care homes that the NHS [place name] will pay for, but nobody's come back to me". Because they don't want- don't want to come back to me, because nobody liaises with you, there's absolutely no liaison. (Viv, FG2)

We can see here that Viv uses active voicing to bring a sense of immediacy and facticity to her account of her attempt to gain information from the NHS continuing care team who were funding her husband's care. At this point, she was trying to ascertain which care homes in her local area they felt would be suitable to care for her husband as she was 'beginning to check out these homes, which is a very depressing experience'. Viv explicitly highlights the lack of parity in treatment between herself as a carer ('the client') and a range of different health and social care professionals. Her use of a three-part list (social worker, memory service or GP) is a robust rhetorical strategy often seen in political discourse to persuade the audience of the speaker's position (Atkinson and Heritage, 1984). It functions here to strengthen the contrast between communication between the professionals and lack of communication to 'the client'. In terms of lexical choice 'the client' (rather than, for example, 'carer' or 'customer') implies that she is a customer – and by implication entitled to good service - but without stating that case too baldly. She builds the argument that the compartmentalisation of services and exclusion from them is endemic through the extremity of her language (e.g., 'nothing', 'nobody', 'absolutely') and also through positioning this sense of exclusion as typical and expected (e.g., 'obviously nobody'). In the previous theme we introduced Carlos' difficulties in accessing appropriate and timely support and resources to facilitate his caring for his father in his own home. In Extract 4 below Carlos and Anne describe the sequence of interactions they had with different professionals, which underscores the hindrance that results from the compartmentalisation of services.

Extract 4

CA: And it took me three months to get these two- these two organised. The first one was the isolating mattress and then the second one was the hoist and I had to get two- two different um, er OTs, occupational therapists…

AN: That's right, yeah.

CA: …to come out. I says "Well while you're here can't you get me a hoist?" "Oh no, that belongs to another section." And you've got to- you've got to get rude. It gets- it gets to the point, well I

don't like being rude, but it gets to the point where you've got to start swearing on the phone to- to get what you want.

EP: Yeah.

CA: Er, in the end I just rang them back up, I says "There's no need to- to bring 'em, he's passed away yesterday, so keep- keep the stuff."

EP: Yeah, that's awful.

CA: It's too late. Why the- why does the system take so long for something to arrive? [...] And there's more frustration there than actually looking after the people that, that-

AN: Well it just tips the balance doesn't it.

EP: Yeah.

CA: the- the- the care.

AN: You're caring, but then this, it just makes you realise-

CA: You don't need that-

AN: how, you know.

CA: they're- they're supposed to be there to help you.

AN: Yeah.

EP: Yeah.

CA: But they're not really because they're- they're hindering you more than anything else. (Carlos & Anne, I2)

As we can see in Extract 4, the sense of frustration with services is palpable in the linear account of the sequence of events that unfolded at the end of Carlos' father's journey with dementia. Elsewhere in their interview Carlos and Anne contrast their experience of caring for a person with dementia with that of caring for Carlos' mother who was discharged from hospital with end-stage terminal cancer and 'everything was delivered, everything was there ready…literally she came in the hospital bed'. Here, Carlos self-repairs the phrase 'you've got to get rude' to strengthen the point that the ongoing and protracted difficulties with services mean interactional conflict becomes inevitable ('it gets to the point'). Through use of the word 'got' he externalises being 'rude' and 'swearing' to the situation rather than attributing his behaviour to personal characteristics, for instance. The desperation of the situation is highlighted in the contrast between the untimeliness of the provision of services, his father's death in the interim and the rhetorical question ('why does the system take so long for something to arrive?') which demonstrate an elemental lack of comprehension about the workings of 'the system'.

These participants, who were caring for a partner or parent, in either their own home or a care home generally wanted to be more included in communication with care providers but often felt excluded: 'whenever I asked for anything, social services, GP, I'd feel like I was being ignored and ignored not accidentally, but ignored on purpose for financial reasons, because it costs a lot of money to provide that support' (James, FG2). James, here, explicitly constructs the problem as one of lack of resources, and other participants too were unambiguous that: 'it's the financial criteria that is sort of

like driving everything' (Victoria, I1). As we have already outlined, carers expressed frustration when services were not "joined up". Many participants also articulated that the abilities of the person they care for were underestimated because of their diagnosis, and rehabilitation services were typically refused: 'the consultant rang me and said [my husband] was "incapable of learning or retaining anything, so there's no point in you having physiotherapy"' (Margaret, FG4).

Extract 5

She's been pretty cheap for the NHS up to this point, isn't she entitled now to sort of like a bit more input than there is? But it all- there just like seems to be no concept of sort of like, well maybe it's luck of the draw, it might be if you live in a different part of the country, because it's like here nobody like has talked about sort of physiotherapy type stuff, occupational therapy type stuff, nobody's talked to her about like counselling. Cos I- I also thought that- I thought nobody's talking to her about how she's psychologically coping with the experience of, you're disintegrating as a person. That's awful isn't it? (Victoria, I1)

We can see here that Victoria positions the responsibility for care provision in the health rather than social care sector. She displays awareness of the complexities (and vagaries) of access to services in terms of geography and 'luck' to add weight to the persuasive contrast with a range of important rehabilitative services. Her use of the phrase 'type stuff' could signal both the potential expansiveness of these types of services and also their lack of comprehensibility and specificity within the dementia care realm. By flagging these areas as conceptually absent ('no concept'), rather than just, for instance, known but unavailable in her area, she implies an almost blue-skies-thinking to the suggestions she is making regarding dementia care. The inappropriateness of this lack of service availability for her mother is demonstrated through the contrast with the horrific notion of 'disintegrating as a person' – a notion that suggests processes of inevitable decaying and unravelling which 'nobody' is facilitating her 'coping' with. In the first two themes we have seen how these participants constructed their dealings with health and social care services as a maze and as difficult to navigate because of their fragmentary nature and gaps in service provision and availability. In the final theme we scrutinise more closely the ways in which the metaphors of battle and fighting were deployed by the carers in their talk about their experiences advocating for services on behalf of the person living with dementia that they were caring for.

Battle and Fighting Discourse

Many carers described the process of accessing health and social care services for the person they care for as a 'battle' or 'fight'. They 'often have to jump up and down' (Jean, FG3) to get the help they need. Indeed this battle with services often eclipsed the illness itself. As Carlos highlighted above the battle is not constructed as being with dementia (unlike cancer e.g., Penson et al., 2004), but with the services to get support for the person living with dementia. Angela, in Extract 6 below, was not alone in highlighting that there were 'good' individuals working in health care, social care and the third sector but that this did not ameliorate the systemic problems encountered with dementia care.

Extract 6

I think there's lots of good people working in the system at different levels but unfortunately there are also a lot of very weak links. And if you're lucky enough to get with one of the good ones you're laughing, but if you're with one of the weak links it's tough. And you don't know- there needs to be the, if you like, the idiot's guide to caring which tells you everything in words of one syllable [laughs] with phone calls that you can get through and speak to a human being instead of a- [laughs] You know, it- it- because you feel as though you have to fight for everything and you shouldn't have to do that. You're in a stressed enough situation without having to go through that as well. Um, and no, there's not enough money but there's an awful lot of money wasted [laughs]. (Angela, FG3)

The importance of getting a 'good one' - a health or social care professional who can facilitate navigating the system and accessing services – is contrasted with the difficulties of the situation in Angela's account here. She refers, as did Jonathan and Victoria earlier, to 'luck' being central to having a positive experience with service providers (the vagaries of this perhaps are further signalled in what might have been 'what you're going to get' when she cuts off and self-repairs at 'you don't know'). Her talk here is also reminiscent of Jan (Extract 2), in that the difficulty getting what is needed from services is felt ('you feel as though you have to fight for everything') in a way that implies that this additional difficulty constitutes "the final straw". Again Angela uses the extreme case formulation ('everything') to strength her claim here, and of course 'fight' quite directly indicates difficulty, conflict and combat. In Extract 7, below, James likens battling 'the system' to 'World War III'.

Extract 7

You're under immense strain caring for somebody who has, in effect, behavioural difficulties through no fault of their own and you're under that mental, emotional, physical effort and at the same time you're having to battle the system and like we've all said, you're having to go to- it's like being in World War III, you'll go into one battle and another one starts. (James, FG2)

Carer burden is very well established and documented in dementia care (Etters et al., 2008) and again we see James juxtaposing the 'immense strain' of caring with the problem of accessing and securing appropriate health and social care. James steps back somewhat from the battling metaphor in that he cuts off and self-repairs at 'you're having to go to-' what might have ended with the word 'war'. Constructing a carer as actually going to war could have been heard by the other focus group participants as too extreme, so he frames the situation somewhat differently as 'being in World War III'. The World War III metaphor enables him to convey the onslaught of negotiating and accessing dementia care and services for the carer and he does so in a way that locates all the carers in the group ('like we've all said') as sharing this extreme form of battling.

Carers also suggested that support was easier to organise in a crisis situation, or at a point when they were unable to cope rather than being put in place and planned appropriately. In some cases, it was reported that a crisis was 'engineered' through needs assessments in order to access respite: 'in that emergency time situation, things can get put together very well. My care coordinator was trying to request respite for me months ahead of when I would be going to take it. And she was fighting a losing battle, so in the end, she put in for emergency respite, and it worked' (Peter, FG1). This example from Peter was one of the few occasions where participants intimated that professionals had difficulties navigating health or social care systems, and of course here, the professional is positioned as being strategic, and successful in her approach. We would not want to suggest that the 'fight' or 'battle' metaphor was used in the same way by all participants, or necessarily always for similarly purposes. Likewise the three themes that we have discussed here have, in a sense, been artificially compartmentalised and were intertwined and mutually informed and effecting in these carers' accounts. Taken together, however, these themes in the participants' talk present a compelling picture of struggle in the contemporary experiences of informal and familial carers of people living with dementia.

Discussion

Findings from this research demonstrate that family carers of people with dementia often struggle to access support from 'the system' that is valuable to them and helps them to carry out their caring role effectively. Participants in this study construct health and social care service provision for people with dementia as unknown, impenetrable, and confusing. Our findings echo one of the four main themes identified in a small scale Australian focus group study with 15 carers of people with dementia - 'frustration and confusion with a system in apparent disarray'- and a subtheme 'making

sense of the system' (Robinson et al., 2009), but provide a more nuanced account of how these issues are constructed in carers' talk. Our participants regularly reported being unable to access appropriate services, being actively turned away by service providers and being refused help. The problems reported by carers were most prevalent in the state-funded care sector, though difficulties with third sector and private sector care provision were also reported by participants. Given the value of informal care provision, which is estimated to save the UK over £8 billion per annum (Alzheimer's Society, 2012), and the proven relationship between caregiver burden and early nursing home placement (Etters et al., 2008), improving carers' experiences of navigating the support services available must be a priority for dementia care support providers, and governmental policy makers.

Previous literature addressing carers of people with dementia and service use suggested that carers did not use services for several reasons, the most common of which were: first, the carer did not feel they needed the services on offer; and second, the care recipient was reluctant to use the service (Brodaty et al., 2005). In contrast, the key discourse our participants drew on was that services were difficult to find, inaccessible to them, or did not offer the type of support they needed. Cutting across these discursive themes of 'the maze' 'beyond our remit' and 'battling the system', many of our participants drew on discourses of 'luck' rather than entitlement, to describe when support was accessed that assisted them in their caregiving role. Carers who described their experience as 'lucky' were generally those for whom high levels of support or public funding had been made available to support the people they care for. For those who reported that they had not been 'lucky' in accessing services, this discourse suggests that there is a lack of transparency or equality in the system, and that they are unclear about their rights or entitlements to services. These data highlight experiences similar to the 'ambiguous gain' identified by Lloyd and Stirling (2011). Our findings demonstrate a clear disparity between common sense understandings of appropriate service provision from carers' perspectives and the institutional rationalities of service providers. Problems accessing appropriate support are common within dementia care services, and may be related to the piecemeal and complex nature of the support services that have built up to support people with dementia. Despite the aims of the National Dementia Strategy (Department of Health, 2009) to standardise service availability, service provision in dementia care remains highly variable by geographical area and funding status. Given this variability, the 'maze-like' nature of the system is particularly problematic. In addition, some participants in our research reported perceiving that public services (particularly those provided by social services and NHS continuing care teams) were specifically designed to exclude them, or that highly necessary support was withheld from them until the last possible moment for financial reasons.

Many participants expressed difficulties in knowing where to turn or who to contact when they needed help. Carers who had access to a social worker, Community Psychiatric Nurse (CPN) or a care team generally seemed to find navigating the system easier than those who did not. A desire for access to a knowledgeable professional to provide continuity, guidance and support on an ongoing basis was palpable in these data (Doherty et al., 2009). These data are resonant with broader societal thinking about dementia care provision, especially (but not exclusively) in the third sector. The Alzheimer's Society, which is England's 'leading care and research charity' in this field provide a Dementia Advisor service, which aims to provide 'quality information and signposting to people with dementia and their carers and families'. However, the charity is explicit that their advisors do 'not provide on-going intensive support, case management, brokerage or advocacy' (Alzheimer's Society, 2009) and the service is geographically varied. Similarly, Dementia UK, another key dementia charity provides the Admiral Nurse scheme, which provides access to mental health nurses specialising in dementia (http://www.dementiauk.org/what-we-do/admiral-nurses/) but this service is only available in certain parts of England.

Conclusion

In conclusion, our findings demonstrate that the reasons for carers of people with dementia having reportedly poor take up of services are more complex than previous literature suggests. Rather than refusing services, carers of people with dementia, who are often under a great deal of perceived strain, find accessing support services challenging and stressful. There are a number of limitations to this project, firstly that the participants were self-selecting and accessed through gatekeeper support organisations (e.g., Alzheimer's Society). These findings cannot, therefore, be generalised to all carers of people with dementia. Importantly, however, the participants in this research were predominantly those who already had access to some forms of support through these gatekeeper organisations – it remains possible that carers who do not access third sector support services are even more isolated or under even greater levels of strain. Further research is needed to provide representative information about carers' experiences of accessing support services. Second, because of the geographical diversity of participants, it is not possible to map questionnaire responses or focus group and interview data directly onto specific services. It is therefore impossible to tell from this research whether these participants might have more access to services than they articulated, which providers of services are most likely to provide either helpful or unhelpful levels of support to carers of people with dementia, or what level of support services would be viewed by carers as appropriate.

Nevertheless, this research highlights that many carers experience difficulties with accessing the services and support that would make their informal and familial carer roles easier. They describe the process of accessing services as time-consuming, unpredictable and often as more difficult than the caring roles they undertake. There needs to be greater access to advice and support that will help informal carers navigate the increasingly complex range of private, third sector and public service providers that comprise the contemporary health and social care system. The difficulties that carers report in accessing services to help them in their vital role must be taken seriously by policy makers in any reform of the social care system. Indeed, if the aim of the recent English social care white paper (HM Government, 2012: 3) 'to prevent, postpone and minimise people's need for formal care' is to be fulfilled, then methods of providing easy access to appropriate support, guidance and services for carers will need to be made central to any plans for reform of the social care sector.

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